

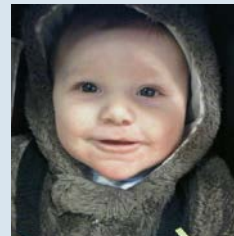


The Cleft Collective

Closing the Gap in Cleft Research

A Healing Foundation Initiative

The world's largest
cleft lip and palate
research programme



Newsletter from the Bristol Research Team

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Investigating the causes of cleft, the best treatments for cleft and the long-term impact of cleft on the family

In this Issue:

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Research milestones

Wishing all of our followers a very Happy New Year! The Cleft Collective Cohort Studies have had another busy six months. Cleft teams in Birmingham, Swansea, Guy's and St. Thomas', Bristol, Manchester, Great Ormond Street, Oxford, Nottingham, Edinburgh, Salisbury, Chelmsford and Liverpool are now recruiting families. Cleft teams in Cambridge, Belfast and Newcastle are also on track to begin recruiting in the coming months.

We now have recruited just over 2,650 individuals (including mothers, fathers, children with cleft and siblings) from almost 940 families.

Birmingham, Swansea, Guy's and St Thomas', Bristol, Great Ormond Street, Salisbury, Oxford and Chelmsford are also recruiting to The Cleft Collective Speech and Language Study.

Once again, the research team is extremely grateful to everyone involved.

The Cleft Collective Christmas Album

Christmas may be over but we couldn't resist sharing some of our favourite Christmas-themed photographs!
Thank you to everyone who contributed.



To submit your photographs to our image bank,
email: cleft-collective@bristol.ac.uk or visit us on Facebook.

Calling all participants!

A huge thank you for your participation in The Cleft Collective Cohort Studies!

Have you received a Starter Pack from us?

Your checklist:

- 1) Complete and return consent forms to your cleft team
- 2) Complete and return questionnaires to The Cleft Collective (**you will be entered into our prize draw!**)
- 3) Take saliva samples using the kits provided and return to the labs at the University of Bristol



Have any questions for us, want to check your status in the study or recently moved home?

Please get in touch using the contact details provided above.

Congratulations Nicky Rumsey OBE!

Nicky Rumsey is Professor of Appearance Psychology and Co-Director of the Centre for Appearance Research (CAR), which she founded at the University of the West of England in 1992. Nicky's research has resulted in the development of interventions and changes in service provision that have made a real difference to those affected by appearance concerns, both in the UK and around the world.

Nicky was awarded an OBE in the New Year's Honours List for her "Services to People Affected by an Altered Appearance". Nicky said she was "surprised, delighted, humbled and honoured by the award.....!" She is keen to stress that the achievements by researchers at CAR have not been hers alone. However, on this particular occasion she is very happy to "take one for the team". Nicky remains an inspiration to her colleagues and students, whom are extremely proud of her achievement.





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What to expect from The Cleft Collective in 2016

With the Birth and Five-Year-Old Cohort Studies and the Speech and Language Study now up and running, we're hoping to expand the research programme in 2016 and begin recruiting families shortly after an antenatal diagnosis of cleft. Information collected during pregnancy will be especially important in helping us to address the genetic and environmental causes of cleft, as well as to identify any additional support that families may need at this time.

We will soon begin to send out questionnaire packs to parents of 3-year-olds, and parents of 8-year-olds. This year will also be the first that we collect information from the children themselves.

We're also beginning to formulate an exciting research agenda, based on the research questions important to individuals born with cleft, their parents and the clinicians who deliver cleft services. For more information about our research programme, or to get involved, please get in touch with us: cleft-collective@bristol.ac.uk.



Using genetics to study the causes and consequences of cleft lip/palate

We are embarking on an exciting new project that uses cutting-edge genetics to help answer the questions: "Which environmental factors cause cleft lip/palate?" and "Are children born with cleft lip/palate predisposed to other adverse outcomes later in life?" This research has the potential to inform public health advice regarding risk factors for cleft lip/palate and improve educational and other outcomes for children born with cleft. We are also creating links with other groups working on the genetics of cleft to collaborate on this and other genetics projects. Welcome to PhD student [Laurence Howe](#) who recently joined the team.

Understanding speech and language development in children born with cleft palate

The Cleft Collective Speech and Language Study has been recruiting for one year now! This study is recruiting babies from the Cleft Collective Birth Cohort who were born with a cleft palate and will collect data on their speech and language development over their first three years. More than 130 parents and children have been recruited so far from six regional centres. Five more centres are due to start recruiting in the next few months. For more information, please contact Dr Yvonne Wren at: yvonne.wren@speech-therapy.org.uk.

Achieving your potential: The impact of cleft lip/palate on school experiences and career aspirations

We recently finished interviewing young people, their parents and their teachers about the different aspects of growing up with a cleft which may impact upon the school experience, educational outcomes and career aspirations. We are now analysing this data and will share our research findings over the next few months. A huge thank you to everyone who took part. Welcome to PhD student [Matthew Ridley](#) who recently joined the Psychology team.

"Appearance Matters: The podcast!"

The Centre for Appearance Research has launched a **brand new podcast**, discussing all things related to how we look! Listen to the first few episodes now on **Soundcloud**: <https://soundcloud.com/appearance-matters> or **iTunes**, and listen out for a **special cleft lip/palate episode** which will be released next month!



"Taking control" CLAPA conference 2015

We were pleased to attend the annual CLAPA conference in November, which becomes bigger and more ambitious every year! This year's theme was 'Taking Control' and we were very grateful to our lead Patient Representative [Rachel McDermott](#), who gave a fantastic talk on how to influence the direction of research. You can watch Rachel's talk, along with the other inspiring presentations from the conference here:

<https://www.clapa.com/about-us/what-we-do/clapas-annual-conference/>

We also held a workshop on how to optimise educational outcomes and improve school experiences. Thank you to the young people, adults, parents and health professionals who attended and contributed – the workshop was hugely popular and we received great feedback.

Latest research updates

NEWS in brief...

- CLAPA have launched their new website and we love it! Take a look here: www.clapa.com.
- A fond farewell to Kenny Ardouin, CEO of Cleft New Zealand, and a warm welcome to Natasha Smith: <http://www.cleft.org.nz>.
- Thank you to the Bristol Plastic Surgery & Burns Research Group, and to Cleft Net East for inviting us to speak at recent meetings.
- The CLAPA Regional Coordinators Project (end of Year Three) report is now available. Learn more here: <http://bit.ly/1RnA4La>.
- The Cleft Clinical Studies Group will be hosting an event for early career researchers in February: <http://bit.ly/1URxNG5>.